

“Some people are not allowed to love”: Intimate citizenship in the lives of people labelled with intellectual disabilities

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Points of interest

- Disability allows a space to disrupt images of the ‘ideal’ citizen;
- Intimate citizenship is often ignored by people working with people labeled with intellectual disabilities and in research;
- We held a workshop in Toronto, Canada, to talk about intimate citizenship;
- In this article, we share what we learned about love, work and consuming in the lives of people labelled with intellectual disabilities.

Introduction

The authors of this paper write from Canada and England. We share a global North location in which, in neoliberal times, the rights and responsibilities assigned to those lucky enough to be included in the category of ‘citizen’ are constantly being contested. As neoliberal governments desire active citizens who are compliant to the needs of the state, this seemingly naturalized image of the ideal citizen has come to dominate popular culture and social policy.

Recently, writers from a critical disability studies perspective have sought to harness disability’s disruptive potential to challenge the myth of the ideal white, male, middle-class, heteronormative, and ‘able’ citizen (Goodley and Runswick-Cole, 2014). By naming and shaming neoliberal ableism (Goodley, 2014) and austerity-as-ideology (Goodley, Lawthom and Runswick-Cole, 2014), it is possible to expose and disrupt the contemporary preoccupation with sorting some people as ‘scroungers’ who, unlike ‘strivers’, *benefit* from the generosity of the welfare state.

We know that people with the label of intellectual disabilities (hereby “labelled people”¹) are experiencing urgent material threats to their well-being and, indeed, to their lives in a time of global economic crisis. The *Confidential Inquiry Into the Deaths of People with Intellectual Disabilities* (Heslop et al., 2014) found that labelled men died on average 13 years sooner than non-disabled men, and labelled women 20 years sooner. In England, Duffy (2013) has painstakingly documented the ways in which funding cuts target poor people and disabled people. In Canada, labelled people more than double their non-disabled counterparts among those living below the poverty line (Council of Canadians with Disabilities, 2015). Labelled

parents are increasingly over-represented among families targeted for child welfare intervention (McConnell, Feldman & Prasad, 2011). As a settler state, these marginalizing experiences reflect and exacerbate colonial practices for Aboriginal and racialized people who are disproportionately labelled with intellectual and developmental disabilities (Salmon, 2011). These material threats are serious and urgent but here we argue that we also need to *make space* for those aspects of citizenship going beyond, as well as intersecting with, material disadvantage, that have so often been denied labelled people.

What is intimate citizenship?

Intimate citizenshipⁱⁱ concerns our rights and responsibilities to make personal and private decisions about with whom and how we are in intimate relations (Plummer 2003). Intimate citizenship is fragile in the lives of labelled people, despite the fact that rights to pursue several spheres of intimate life, including sexual identity and expression, friendship, marriage and cohabitation, family life and parenthood, are enshrined in the UN Convention of the Rights of Persons with Disabilities (UNCRPD, 2007). These rights matter because intimate relationships establish the social networks necessary to support employment, educational success, secure housing, family stability, sexual health and wellbeing, and build resilience against the deleterious effects of structural and interpersonal ableism. Barriers to intimate ties lead to social and economic costs associated with vulnerability to abuse and violence, child welfare involvement, trans-institutionalization and reliance on private and social care resources.

And yet, little detailed exploration of labelled people's experiences of intimate citizenship has been undertaken. We know little about the spaces people may easily access and claim, and how these may shape intimate subjectivities, relations and practice; nor do we know what new ableisms (the exclusions, disadvantages and silencing of people with impairments) or other barriers are encountered within the exercise of intimate rights. Importantly, our knowledge rarely includes labelled people as competent commentators on their own life conditions.

Making Space for Intimate Citizenship

With these issues firmly in mind, we worked to bring together self-advocates labelled with intellectual disabilities, academics, service providers, Aboriginal leaders, students, and artists to take part in a three-day workshop to begin to explore intimate citizenship in Toronto, Canada in September 2015.

The event was an opportunity to develop reciprocal relationships between academic, community and self-advocate collaborators. To this end, we innovatively employed facilitated arts-based techniques to enhance access to conceptual and research discourse that typically marginalizes labelled people (and others). Engaging all participants in embodied, aesthetic activities lessened the hold of pre-given cognitive frameworks in favour of interactions based in emotion and play – possibly more in keeping with the substance of intimacy. The workshop was organized around three salient dimensions of human citizenship: Loving; Labouring; and Consuming.

Knowledge shared at this event formed the content for a public Virtual Hub, housing an array of research and other resources related to intellectual disability and intimate citizenshipⁱⁱⁱ. Here we share our learning from each of the three dimensions in turn, though we acknowledge that these intersect in myriad ways within labelled people's lives.

Loving

Loving relationships enable us to stay connected with one another, and may protect us from being treated unfairly and from loneliness and violence. Sadly, we know that intimate relationships can also be the sites of abuse, isolation and hostility.

In our workshops, participants described the ways in which labelled people are 'not allowed to love' – prevented from having friendships, relationships and from bringing up their children. The central role of family members was identified as a key determinant of people's intimate lives. This linked to a discussion of the ways in which 'love' can morph into violence and control of disabled people's bodies in ways that leave life-long scars. Stories of forced sterilization and the removal of children (initiated in some cases by family members) haunted discussions of 'love', revealing the urgent need to re-imagine parenting and partnerships in the lives of labeled people.

While love is often commonly associated with ideas of desire and of wanting, discussions touched on loving being as much about giving to others as receiving. When regarded as passive recipients of care, labelled people are not allowed to *give*, not allowed to love. Discussions concluded with the claim that intimate relationships in the lives of labelled people must be claimed as a right and as a matter of disability justice.

Working

Caring for others and ourselves involves *work*. Intimate work is seldom talked about or the subject of research, particularly in the context of disability, although there are exceptions (Liddiard, 2014). Labelled people are often thought of only as those who are cared for, rather than as people who care (Fudge Schormans, 2015). The opportunity for paid work is often promised to labelled people but is often denied. Exclusion from the labour market can also lead to exclusion from the category of citizen, and consequent denial of associated rights and responsibilities (Goodley, Runswick-Cole and Bates, under review).

While many disabled people desire work and report on the ways in which work allows people to feel valued and to make friendships and relationships, disability, and disability studies, were identified as the best places to broaden and trouble notions of work in neo-capitalist societies. Not least, disability forces us to re-engage with and to disrupt notions of care and work in disabled people's intimate lives.

Consuming

Labelled people consume a host of services, goods and support, but, unlike other people, they are often characterized as consuming too much; they stand accused of burdening the fragile economies of the global North. Disabled people's contribution to the economy (in generating opportunities for other people to have jobs, provide services and resources and as workers and employers themselves) is typically ignored. Also discussed were the forms of consumption that are required by intimate citizenship; that is, what we need to buy, shop, consume, or *have* in order to be intimate with others and ourselves. Dialogues here connected the material conditions of life with intimate and loving ones. For example, how do people who are under-housed/homeless maintain intimate ties with lovers, friends, and family? Does experiencing hunger and an under-heated house negate desire for sex, affection and closeness? How is our intimate citizenship produced by practices centred on the appearance of the body: choosing our own (age-appropriate) clothes; affording beauty and hygiene products; accessing dental and health care – all of which cost money?

And while there is more to life than shopping, the basic levels of material deprivation in the lives of labeled people across the globe remains an urgent cause for concern.

Conclusion

The aim of the workshop was to stimulate discussion and debate. From these discussions we were left with questions, rather than answers. So, in the spirit of the workshop, we leave you with questions to ponder:

1. How can we make ‘real’ the claim that intimate relationships are a right in the lives of disabled people?
2. How can we create spaces for labelled people to work, while at the same time valuing other forms of activity, including care?
3. How can we re-imagine consumption in ways that recognize the contribution of disabled people while simultaneously challenging the many material exclusions in their lives?
4. How can we even begin to talk about intimate citizenship and rights at a time of crisis in states that are failing?
5. What is the place of intimate citizenship in settler-colonial states?
6. How can we start to think about intimate citizenship in the many contexts where ableist desires continue to cancel out the desires of disabled people?

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i We use the term “labelled people” in this article to refer to people who have been labelled with intellectual impairments/disabilities because it is the prevalent terminology in North America.

ii For an accessible account of intimate citizenship visit:

<https://bigsocietydis.wordpress.com/2015/05/20/intimate-citizenship-and-learning-disability/>

iii <http://makingspaceforintimatecitizenship.wordpress.com>